

Iron Filings

Providing information, awareness and support

Firefighter's Iron Levels Reach Flash Point

Over a year ago, depression, mood swings, extreme fatigue, and emotional outbursts all made it difficult for Keith Kauk to live what used to be a healthy, vibrant life. Keith normally loved being with his friends and family, working at his job as a Winnipeg firefighter, golfing and curling. He especially enjoyed canoeing and horseback riding in the company of his wife, Barb, as they "land cruised" with their camper. His illness changed all of that, and debilitated him.



A story from Manitoba

Everyone had thought that Keith's condition was caused by drinking. Barb stood by her husband through his seemingly unexplainable, erratic behavior.

Keith was prescribed anti-depressants but was still plagued with fatigue. Consequently, blood tests were taken, and they showed an extremely elevated serum ferritin level. Keith was referred to a hematologist for further investigation.

In April 2011, Keith was found to have a serum ferritin level of 4526 ng/ml and a genetic combination of the C282Y/H63D mutations. There was finally an explanation for Keith's negative change in personality. He was the victim of hereditary hemochromatosis.

Keith took a sick leave from work, but the fire department wasn't the only place where his absence left a void. He temporarily removed himself from duties on the Executive Committee of the Manitoba Fire Fighter's Curling Association (MFFCA), and his fatigue meant he couldn't help maintain his neighbour's yard as he had done for years past.

Keith Kauk back at work at his fire hall

Keith was put on weekly phlebotomies. His first phlebotomy made him vomit, and he was exhausted for three days afterward. After his second phlebotomy, he was weak and had little appetite. Keith recalls having a "terrible, terrible feeling". He seemed to be going downhill rapidly.

Keith's state alarmed Barb. "I got so scared for him and felt so helpless that I couldn't make it better. I found myself getting very angry that this was happening to him and to us." Things did not seem better after his fifth phlebotomy. He was still extremely tired, and his appetite went from one extreme to the other. "There were days where he would eat next to nothing and nights when he was starving."



You can help **iron out Hemochromatosis** in Canada.
Find out more at www.toomuchiron.ca

Firefighter's Iron Levels Reach Flash Point (CONTINUED)

Nausea, weight loss, exhaustion and frequent napping all caused great concern for Keith and Barb as to whether the phlebotomies were really working. Keith wondered, "Am I ever going to get better?"

Keith marched onward with his phlebotomies. The support he received from his fellow firefighters was "fantastic". His biggest support came from his wife who unfailingly stood by him. Upon Keith's diagnosis, Barb had made contact with the Canadian Hemochromatosis Society for information and support which she could use to help and encourage Keith through his treatment. In search of others with hemochromatosis, they also found help through an online support group.

Finally, in June, Keith felt much better. He had more energy and was able to mow his lawn without becoming exhausted. By mid August, he was de-ironed. "I was still experiencing fatigue," relates Keith. "I had a lot of muscle spasms and would have a tremor when I was really tired, but it has calmed down since then."

During Keith's treatment, he discovered that one of his uncles on his father's side has hemochromatosis too. His uncle had been diagnosed in 1994 but, not knowing the hereditary nature of it, made no effort to alert his relatives. "We were both stunned," says Barb. "Nobody in the family knew that Uncle Wally had this; therefore no testing was ever done with his other siblings. If the technology had been up to speed and Wally's doc had been on the ball, Keith would not have gone through the pain that he did."

Since Keith's diagnosis, a sister and a brother have both been found to be homozygous for the C282Y mutation and are undergoing weekly phlebotomies. Another brother has the same genetic combination as Keith. Yet another brother and sister are heterozygous for the C282Y mutation. Examining the genetics of himself and his siblings has led Keith to realize that one of his parents had the C282Y/H63D combination (most likely his father who had passed away eight years earlier from complications caused by Parkinson's Disease), and the other must have been heterozygous for the C282Y mutation.

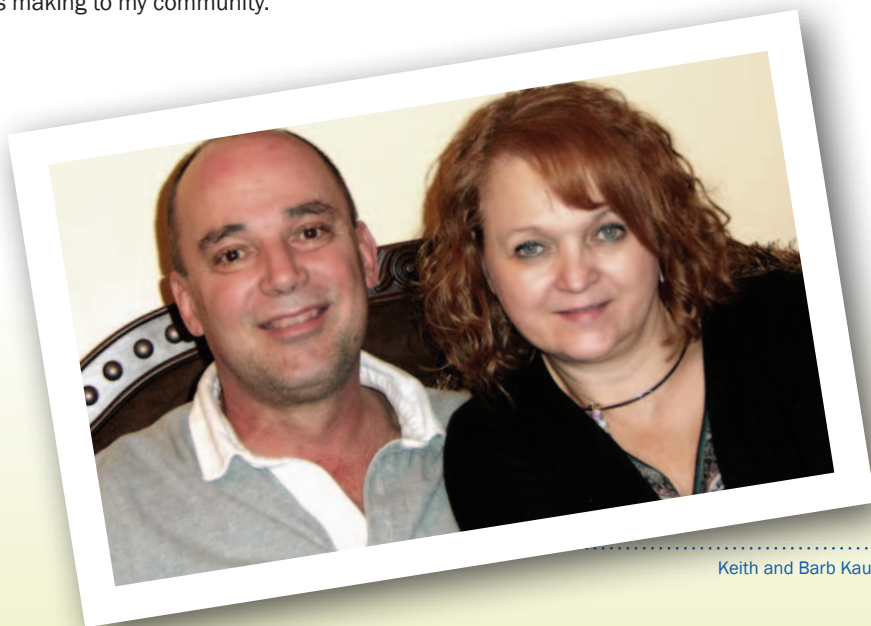
Keith and Barb's new found knowledge overwhelms them. While they are upset for the suffering that they've experienced, they are grateful that they can help save Keith's siblings from the experience. All of his cousins have been notified of their potential risk for hemochromatosis in hopes of preventing the same fate as his, or even worse, his father's.

Keith went back to work last August, fighting fires and saving other people's lives and property. "I was extremely pleased to go back. I love what I do and I missed the camaraderie as well as the contribution I was making to my community."

His fire hall was also glad to have him back. With hemochromatosis now on the radar, many of his fellow firefighters ask him about his illness and treatments. Back with the MFFCA, Keith will be a volunteer at the 2014 Canadian Fire Fighters Curling Championship.

Keith's wife might be the one most grateful to have him well again. "It is wonderful having my 'old Keith' back," Barb confides. "It was very scary before we knew what was going on with him and I did not think that things could ever be normal again. It was a huge relief to know that this is something that was treatable. The more he was de-ironed, the more I saw 'him' come back to me."

In July, Keith and Barb are taking advantage of both of their healthy lives by going on a vacation to Wales.



Keith and Barb Kauk

CHS Serves and Supports

BOB ROGERS, CANADIAN HEMOCHROMATOSIS SOCIETY
EXECUTIVE DIRECTOR AND CEO



CHS operates several programs throughout Canada to assist those at risk of hereditary hemochromatosis (iron overload). The programs include Community Outreach, Patient Support, Medical Referral and a Volunteer Program, all focused on national information and awareness. In this edition of Iron Filings, I want to give you a few examples of those who have used our Patient Support program.

About a year ago I received an urgent telephone call from Barb Kauk. Her husband Keith, a firefighter in Winnipeg, MB, was very ill due to a severe overload of iron in his body. For several weeks Barb, Keith and I spoke over the phone. I was able to provide them with support and information to help them overcome the troubling circumstances they were facing. For the next 6 months we exchanged frequent emails updating Keith's progress. Their story is the feature article of this newsletter. Keith and Barb were never alone in their fight to overcome the ravages of hemochromatosis.

Cindy in St. John, NB, contacted our office and explained that her sister had been diagnosed with hemochromatosis. Cindy,

35 years of age, wanted to know what she should do. Our patient support worker explained that the best medical practices guideline recommends that as a first degree relative, she should have her physician order an HFE genetic test immediately. Her doctor didn't comply with her request, saying it was unnecessary, so Cindy contacted CHS again for help. CHS is so pleased to have a new Corporate Partner, Genetrack Biolabs, who offers an effective, non-invasive and confidential HFE genetic test directly to patients. See more about their services at www.hemochromatosisdna.org or page 7 of this newsletter. Cindy's genetic test results indicated she had two C282Y genes and was slightly overloading in iron. Cindy is currently in treatment and doing well.

Lastly, there is Brad, 29 years of age, who lived in Abbotsford, BC at the time of his first call to CHS. Brad didn't know he had a problem with stored iron in his body until his insurance company's tests indicated he was overloading in iron and provided him rated coverage. Brad's HFE genetic test confirmed he had hemochromatosis. Through CHS's Medical Referral Program, CHS recommended a knowledgeable physician for Brad to visit. Brad got a promotion at

work and is now living in Edmonton, AB. His iron levels have been lowered to normal and he is continuing periodic maintenance treatments. He has reapplied for insurance benefits and because his iron levels are under control, appears to be eligible as a standard risk with a new insurance company.

CHS receives several calls each week from Canadians seeking more information, awareness and support about hemochromatosis. The service and support CHS provides helps create vibrant lives, families and communities by reducing suffering and saving lives. CHS is grateful for the generous financial support we receive to operate and implement our programs. We need your help to continue. Thank you.

Canadian
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Société canadienne de l'hémochromatose

**Provide a lasting contribution
to eliminate the suffering and
diseases caused by iron overload.**

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LEAVE A LEGACY™

Insurance Issues

With questions surrounding insurance coverage commonly arising from patient support calls and information sessions, insurance is a worthy topic of discussion. Here, we explore ways to navigate through the insurance maze.

Peter* in Vancouver had no idea that he had hemochromatosis when he was denied disability insurance. He was young and healthy, with some joint pain in his thumbs and forefingers. The medical exam completed by the insurance company showed high liver enzymes, Peter's first clue to his silent medical condition and the reason for his denied insurance application.

On the other side of the Rockies, Rob, an otherwise healthy Calgarian in his 30's, had been diagnosed with hemochromatosis 18 months prior to his application for term life insurance. He was being monitored by his physician, and his condition was considered stable. Rob was deemed a standard risk and received coverage.

Andrea Shandro, an advisor at Vital Benefits in Calgary, says that when it comes to determining your eligibility for insurance coverage, there are no clear-cut answers. "However, there are factors that improve your chances of obtaining coverage," Shandro elaborates. "These include being diagnosed before the age of 50, completing appropriate testing and follow up, undergoing appropriate treatment and following a favourable lifestyle."

Shandro states that being confirmed to have the genes for hemochromatosis does not automatically discount you from receiving coverage, as was the case with Rob. And if you have not been genetically tested but are being investigated or treated for iron overload, you can bet the insurers will be having a closer look at your medical records.

When it comes to possible outcomes, Shandro says, "Your resulting coverage may be as applied for, or your coverage may be rated, which means you pay more for a given amount of coverage. Other possibilities include having your benefit periods reduced or exclusions applied, your coverage may be

postponed until further investigations are complete, or you may be denied coverage altogether."

Being denied coverage is exactly what fifty-seven year old Roger from Kelowna experienced. Roger was diagnosed 10 years ago with hemochromatosis and confirmed to be homozygous for the C282Y mutation. When he applied for critical illness insurance eight years ago and extended care insurance two years ago, he was declined both times despite having his iron levels under control and exhibiting no symptoms.

Shandro says that if your application is rated or declined, this information is recorded on the Medical Information Bureau (MIB) which can affect your future insurability. A trial application, also known as a pre-underwriting assessment, can be submitted to different carriers to help gauge your likelihood of obtaining coverage without creating an MIB record. Specialty carriers may also be accessed on an as-needed basis if a client is declined.

Interested in submitting a pre-underwriting assessment? Need more information? Contact Andrea Shandro at: ashandro@vitalbenefitsinc.com or 1-877-209-3817.

Download the pre-underwriting assessment form off the CHS website www.toomuchiron.ca.

To increase your chances of obtaining coverage for your insurance needs, Shandro recommends getting an early start, while you are young and healthy. "If you have children, consider starting their insurance program early. Some types of policies can be issued with guaranteed coverage that can be added at future dates without further medical evidence."

If you know that you have a family history of hemochromatosis, but haven't been medically examined for the disorder, you may also consider having a genetic test performed through a private medical lab such as Genetrack Biolabs (see article on page 7, or visit www.hemochromatosisdna.org). With this test, you can confidentially determine your genetic predisposition for hemochromatosis which can then help you decide on your insurance priorities.

*Patient names changed



Newborn saved by heart surgery – and many blood transfusions

Parents Jim and Crystal Mackill are thankful for every day they get to spend with their healthy, active two-year-old son, Wyatt, because if blood was not available when he was born, he might not be around today.

Wyatt was born with a condition called Transposition of the Great Arteries, where the aorta and pulmonary arteries are reversed, depriving the body of much-needed oxygenated blood. At only 14 days old, Wyatt underwent heart surgery and required many units of blood and blood products to make it through the operation safely.

“You can never anticipate your newborn baby going into heart failure and needing major surgery,” says Crystal Mackill, Wyatt’s mother. “I fully believe that without the blood and blood products needed to make his surgery a reality, Wyatt would not be here with us today. My husband and I are so grateful to blood donors and have committed ourselves to regular donation as a result of this experience.”

The Mackills now give back by donating at their local blood donor clinic.

In the Society’s ongoing efforts to inform hemochromatosis patients in the maintenance phase of their treatment that they may be eligible to donate their blood, CHS is pleased to bring you this article from Canadian Blood Services.



Jim and Crystal Mackill
with their son Wyatt

We Surpassed Our Goal!

We are pleased to announce that in 2011, we surpassed our goal of donating 100 units of blood to Canadian Blood Services. Well, we did more than surpass it. We catapulted over the goal and landed at an impressive 147 units, donated by 74 registered members of our Canadian Hemochromatosis Society Partners for Life group. In comparison, we donated 72 units of blood in 2010.

In a letter from Ariella Eini, Canadian Blood Services Partnership Specialist, she writes, “On behalf of Canadian Blood Services, thank you so much for your support! We truly appreciate the partnership we have with the Canadian Hemochromatosis Society. When you consider that one unit (that’s a single donation) can go to three separate hospital patients, you and your organization helped 441 hospital patients in 2011! That’s an amazing

“What a beautiful exchange.... a life-giving product in return for a life-saving procedure!”

— Professor Thomas Bothwell, a world expert on Hemochromatosis, ally and friend of Marie Warder, founder of CHS

and impressive achievement – one you should be incredibly proud of.”

We are very proud of all our friends of the hemochromatosis community who helped CHS reach its goal. Thank you all!

We have set our new goal for 2012 at 150 units. This year to date, members of the CHS Partners for Life group have already given 46 units of blood!

You will soon be seeing the Canadian Hemochromatosis Society’s name behind registration desks at permanent CBS clinics all across Canada. This can

serve as a helpful reminder to register your blood donation through our Partners for Life group when giving blood.

If you haven’t yet registered with the CHS Partners for Life group, you can do so from our website www.toomuchiron.ca or in person at the blood donor clinic. The Partner ID# to use is CANA002257 (four letters and six numbers).



Canadian Blood Services
it's in you to give

Updates

Volunteer Coordinator

CHS has recruited Marilyn Sakiyama who will be responsible for providing coordination of CHS' national group of volunteers. In her role as volunteer coordinator, Marilyn will help recruit, train and support Regional Organizers and other volunteers as they raise awareness of hemochromatosis through activities and events, information sessions, and fundraisers. Through Marilyn's efforts, CHS aims to effectively support a strong network of volunteers who, together, will raise the national profile of hereditary hemochromatosis.

Marilyn comes to us with experience as a senior project manager for the Centre of Applied Research in Mental Health and Addictions and 10 years of experience working as a service director for Muscular Dystrophy Canada.

To become a volunteer, please contact Marilyn at office@toomuchiron.ca or speak with her at 604.279.7135.

Welcome aboard, Marilyn!

Toronto Network Event

On February 1st, CHS held its first ever Network Event in Toronto, ON. This event was an opportunity to network with others who have hemochromatosis and to learn more about the disorder. The turnout was good, despite last minute changes to the venue due to a power outage at the original location. Fortunately, most attendees got the message about the change in venue and were on hand to listen to Patrick Haney, a member of CHS' Board of Directors, speak about the disorder, mingle with the crowd and enjoy light snacks.

Feedback was positive and members of the crowd also showed interest in volunteering for the Society. Good job and thank you to Patrick Haney, Lynn & Allan Day, and Frank Erschen for their work and support for the event!

Support CHS While You Buy Groceries

Everyday shopping can be an easy way to raise additional funds for CHS!

We are pleased to announce that CHS is one of the charities that you can support with your purchase through DonateNaturally.com.

DonateNaturally.com provides all of your favourite natural and organic non-perishable food and household items delivered



conveniently to your front door, Canada-wide. With every purchase, 15% of the value of your order goes to the cause of your choice. You are not charged an additional 15% on top of your order, and items are competitive with those at your local store.

First time buyers are eligible for a special promotion. At the checkout, enter promo code 'TRYIT30' to receive 30% off your first order.

You already shop for your groceries on a weekly basis; why not raise money for CHS while you do so? We thank you!

HBC Reward Points

Did you know that you can donate your HBC reward points from The Bay, Zellers, Fields and Home Outfitters to CHS? CHS uses these points to purchase supplies for program activities, allowing the Society to stretch its valuable dollars. To donate reward points online or in person at a store, you will need CHS' Public ID #: 4275683. Online points donations can be made at www.hbc.com. Thank you again for your support.

May Awareness Month

Awareness Month kicks off a little early this year with a Hemochromatosis Information Workshop being held in Edmonton. This workshop will feature a power-point presentation about hemochromatosis followed by a question and answer period. This event takes place on April 25 at 7PM at the Holiday Inn Express located at 2440 Calgary Trail in South Edmonton. Please RSVP your attendance as soon as possible as space is limited. To RSVP please call 1 877 BAD IRON.

CHS is at the Canadian Home Builders Association of Northern BC (CHBA NBC) Home Show April 27, 28 and 29 at the Prince George Exhibition Grounds. Come visit us in Booth 357 to gather more information on hereditary hemochromatosis and meet Executive Director Bob Rogers. We thank CHBA NBC for their kind support and invitation to participate in this year's home show.

Throughout the year, CHS will be visiting many different towns and cities in British Columbia, Alberta and Ontario to foster awareness of hemochromatosis. Please watch for updates and special event notices on our website www.toomuchiron.ca

What You Can Do For Awareness Month and Throughout the Year

- Send a letter to the editor of your local paper. We have a template available for you to use; all you need to do is add a little information to make it more personal and relevant to your area. Contact us at office@toomuchiron.ca for the template.
- Place brochures or posters at your local drug stores, doctor's office, community centres, workplace or wherever they will let you! Email office@toomuchiron.ca if you would like us to send you some brochures, or download the poster from our website at www.toomuchiron.ca/join/index.php.

- Talk to your family and friends about hereditary hemochromatosis. "Like" us on Facebook (www.facebook.com/TooMuchIron). Join our group on LinkedIn.
- Volunteer to spread awareness year round. Contact our Volunteer Coordinator Marilyn Sakiyama at office@toomuchiron.ca to get started.



DNA 101: DNA Testing for Hemochromatosis

By June Wong, PhD, Vice President, Laboratory Operations, Genetrack Biolabs Inc.

Hereditary hemochromatosis is caused by defects in a gene called HFE. The HFE gene is responsible for regulating the amount of iron that is absorbed from the food that we eat.

DNA testing can determine whether a person may be at risk of developing hemochromatosis.

How does the test work?

The DNA test examines the HFE gene for mutations that cause the gene to become defective.

The HFE gene has three known mutations which cause hemochromatosis, namely C282Y, H63D and S65C. The C282Y mutation is the one most commonly found in individuals with hemochromatosis. DNA testing confirms the presence of the C282Y, H63D and S65C mutations in the HFE gene.

Hereditary hemochromatosis can occur when a person inherits two defective copies of the HFE gene, one from each parent.

Why get tested?

Since hemochromatosis is treatable if detected early, screening for hemochromatosis can prevent potentially fatal complications from occurring. DNA

testing for hemochromatosis is fast, confidential, and can be completed using a simple mouth swab.

Individuals at risk wishing to start a family may also consider testing to determine the likelihood that they will pass a defective HFE gene on to their children.

Early detection can prevent future complications

The best time to get tested is before 30 years of age, so that the disease can be detected before organ damage occurs. When detected and treated early, there is a good chance of avoiding life threatening complications of iron build up in the body later in life. If any family members test positive for an HFE gene mutation, other family members should also be tested.

Getting Tested

DNA testing can be performed at any age, even newborns. DNA is collected using painless buccal (mouth) swabs and submitted to the lab for testing. Confidential results are available in 7 days.

To order a hemochromatosis DNA test or for more information on HFE gene testing, go to www.hemochromatosisdna.org



Canadian
HEMOCHROMATOSIS
S O C I E T Y
Société canadienne de l'hémochromatose

2011

Annual General Meeting

June 27 2012, 5:00 pm PST

Richmond Caring Place
Room 320 - 7000 Minoru Blvd.
Richmond, BC V6Y 3Z5

Membership Required

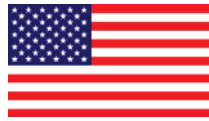
To participate in the Annual General Meeting, you must be a current member of the Canadian Hemochromatosis Society as of Thursday, May 31st, 2012.

Please RSVP by email or phone no later than Thursday, May 31st, 2012 and indicate whether you will attend in person or by teleconference. An AGM meeting package will then be forwarded to you.

604 279 7135 | 1 877 BAD IRON | office@toomuchiron.ca

Heading to the United States?

Preparation beforehand will allow Canadian travelers to the U.S manage their phlebotomies and treat their hemochromatosis while away from home.



Travelers who will need to have their phlebotomies while away in the U.S. can start their search for blood donation centers online: www.americasblood.org and www.redcrossblood.org will provide listings based on the destination zip code. At some of these centers, blood donations for the community blood supply are accepted from hereditary hemochromatosis patients if they meet volunteer donor eligibility requirements.

American Red Cross

The American Red Cross generally does not accept blood donations from hemochromatosis sufferers. However, Red Cross blood collection centers in the Pacific Northwest have a variance issued by the U.S. Food and Drug Administration (FDA) which allows them to accept blood from those with hereditary hemochromatosis. A spokesperson with the Portland Donor Center says, "What this means is that patients who require anything from weekly to one-time phlebotomies can have them performed at one of these centers. The patient will be assessed for eligibility each time and if eligible, will be able to make a blood donation. If the patient is ineligible, their blood will be discarded."

A special Red Cross form entitled "Request for Therapeutic Phlebotomy" needs to be filled out by the patient's physician ahead of time in order for any blood to be drawn. These forms are valid for one year, so will need to be re-submitted if travel plans take the patient into the Pacific Northwest again in the following year. Other Red Cross centers in the United States may also perform therapeutic phlebotomies, but check ahead first.

Independent Blood Banks

Blood banks with the FDA variance will also accept blood donations from eligible hereditary hemochromatosis sufferers. There is no charge for these phlebotomies since the blood can be used for transfusional purposes. On the other hand, therapeutic phlebotomies (where blood cannot be used because certain medications are taken or other eligibility requirements aren't met) may or may not have a fee attached to them depending on the blood bank being attended. Regardless of the type of phlebotomy, physician's orders will need to be submitted before anything can be scheduled. Call ahead to the blood center to determine if the physician's prescription will do or if a form needs to be filled out.

Private blood banks without the FDA variance cannot accept blood donations from those with hereditary hemochromatosis. However, therapeutic phlebotomies can usually be performed based on doctor's orders. Again, phone ahead to the blood center to determine what paperwork is necessary.

Hospitals

A hospital is another possible location to receive a phlebotomy. There are fees associated with this option, and the blood will be discarded.

With the various options available for blood-letting in the United States, travelers need to make sure they understand what is required before they go state-side. United Blood Services is a group of non-profit community blood centers located in 16 states. Barb Kain, Director of PR/Communications at United Blood Services, emphasizes that each blood center may operate slightly differently from the next. "My best advice to your readers is to call ahead and talk with someone at the blood center closest to the area where they're staying."

For a list of American blood centers with the FDA variance, please visit our website at www.toomuchiron.ca.

Call the CHS office if you need more information: 1 877 BAD IRON

Special Acknowledgements

The Canadian Hemochromatosis Society is extremely pleased to acknowledge our 2012 Partners and Corporate Sponsors:

Genetrack Biolabs Inc
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